

WHEN DEMENTIA IS IN THE HOUSE

FOR PARENTS



NICE

National Initiative for the Care of the Elderly

Initiative nationale pour le soin des personnes âgées

We care together

Ensemble pour le bien-être des aînés

www.nicenet.ca

For You, the Parent

Parenting represents one of life's most challenging endeavors. If you manage this while fulfilling the myriad demands of a caregiver to a severely ill spouse, you need support. It's possible to let the emotional needs of your children, who may present themselves as quite independent, slip away in favor of fundamental safety, financial survival, or life and death decisions. But your children require even more of your attention and affection during this time. So this site, drawing on comments from children who care for loved ones with Frontotemporal Dementia (FTD), offers tips to help you navigate unfamiliar territory when everyone is relying on you.

Special Challenges for Parents Who Are Primary FTD Caregivers

When your spouse is diagnosed with a terminal, degenerative illness, you suffer relentless, devastating loss with no apparent resolution long before that person's physical death. You become a full-time caregiver, and when someone young, strong, and mobile suffers from dementia, you can add warden to those duties as well. You must interact with friends and family who don't understand what you are going through, and they may unwittingly underestimate your pain by minimizing the situation ("Well, he seems fine to me! Isn't that encouraging?"). In an instant, you also become a single parent and the primary breadwinner, managing the family's finances and nurturing children who may need more of your time and consideration than ever before. Nothing about this journey is simple or painless. But if you can tend to yourself once in a while, some rewards may surprise you.

WHEN DEMENTIA IS IN THE HOUSE

What You Need to Do for Your Kids

What you need to do for your children, more than anything, is take care of yourself so that you can remain balanced and patient. Children are highly sensitive to your mood, and almost universally, they say that your pain, on top of losing the other parent, can be one of the toughest parts of the whole ordeal. Your stress negatively affects your own health, and deeply influences the well-being of your children.

Arranging for time away from your ill spouse to attend sports and school events and share outings that nurture the relationship with your kids is paramount. Younger children may be more inclined to demand your attention, but adolescents and teens will drift away to “spare” you additional worry. So it’s your responsibility to establish and maintain open communication and unspoken support. In many cases, children are losing one parent; they need to feel confident they will not lose both. But you can’t pass along that assurance with just words.

Kids’ Lives Outside the Home

Nearly all teens say that extracurricular activities help them more than anything else, so this is something to encourage — even if it means enlisting other people to help with driving duties. Sports such as soccer, swimming, basketball, baseball, and hockey provide a reassuring team atmosphere, a healthy escape from the burdens at home, and a strong identity for the child. Others gravitate toward choir, music, theatre, or similar pursuits. Some even find that volunteering helps change their perspective and appreciate the parts of their lives that are going right.

Why It’s Essential to Pace Yourself

By slowing down and taking quiet moments (note: they aren’t distributed; you seize them!) for yourself, making time to exercise, and by asking for help to accomplish these objectives, you set an

essential example for your children. You show them — much more effectively than telling them — that it's acceptable to spend time with friends or pursue activities you enjoy. If children sense your stress and irritability, they will not speak up and share their own pain, for fear of overwhelming someone they want to protect and help. Nor do they want to lose one parent and watch the other descend into martyrdom. How can you alleviate your child's pain if you can't manage your own? Do something each day to take care of yourself, even it's just a 10-minute walk around the block to decompress and find a way to smile. Everyone will benefit.

Expressing Emotions to Your Children

This is tricky. Do you bottle your emotions in an effort to remain “positive” for your children? Is this healthy? Or should you allow your children to see and hear what you're feeling? Not surprisingly, kids say they need a balance. It's fine to break down once in a while and expose your frustration and grief — it's authentic — but you should limit these episodes. They can scare children, who look to you for stability and guidance. At the same time, it's important for them to see (again, what you do is far more powerful than what you say) that it's acceptable to express emotions along the way. This gives them permission to do the same.

Finding Help Outside Your Family

Feeling alone at points along this journey is inevitable. But consider countering those feelings with these ideas:

- ✓ Ask the neurologist to direct you to the nurse or social worker at the clinic who organizes support groups. These professionals also understand every aspect of family trauma associated with dementia, and can serve as valuable resources on all levels.

WHEN DEMENTIA IS IN THE HOUSE

- ✓ Attend a support group in your area or online. Communicating with people who understand exactly what you are feeling can ease the isolation.
- ✓ Ask for a reference to a family therapist/psychologist who understands dementia, and can assist you or your children.
- ✓ Make exercise or your other tried-and-true stress reduction activities critical appointments on your calendar, and get help doing it. Ask friends to meet you each week for early morning walks, enroll in a dance or tai chi class at the community center, join a triathlon or running group. Ask other people to assist you by supervising your loved one during these times. Innovative friends will likely assemble a rotating schedule.
- ✓ When people say, “Let me know if there’s anything I can do to help,” understand that they mean it, express your gratitude, and make it work for you. Rather than feeling frustrated at what may seem like an empty social nicety, ask for specific assistance in a way that empowers everyone. See above example regarding exercise, or ask them to take your ill spouse to lunch or a movie, or spend time at home. Suggest help picking up groceries, running errands, or providing dinner occasionally. You’ll see that people are thrilled when they know what will make a difference.
- ✓ Before social gatherings, you may want to guide family and friends. One husband sent the following suggestions about how best to interact with his wife:
 - » As her disease progresses, we will see less communication initiated by her. She will appear to be distant and indifferent to greetings and questions.
 - » However, she still wants to connect with her family and friends. You have to help make that happen! She is not hard of hearing, just unresponsive, so speak in a clear, normal voice. She will not answer most questions with more than a “yes” or “no.”

- » She likes to walk, but should always be with someone unless she is in the house; even then, keep an eye on her, since she can be elusive.
- » When she eats, make sure that she has small portions. If you are next to her, offer to cut up some pieces so she can eat without a knife.
- » Sometimes she will take your hand, or lightly touch your arms or cheeks. Don't be alarmed. She fondly remembers her connection with you, but she can't tell you this in words, so this is her way of reaching out to you!

Locating Support

- <http://www.caregiver.org/caregiver/jsp/home.jsp>
- <http://www.nfcacares.org/>
- <http://memory.ucsf.edu/>
- <http://ftdsupport.com/side-localsupport.htm>
- <http://www.alz.org/carefinder/support/support1.asp>

Internet Support Groups

- <http://www.ftdsupportforum.com/>
- <http://www.caregiver.com/index.htm>
- <http://www.pdsg.org.uk/forum>
- <http://health.groups.yahoo.com/group/dementia-griefcounseling/?tab=s>
- <http://health.groups.yahoo.com/group/PPA-support/>

WHEN DEMENTIA IS IN THE HOUSE

Discussing Dementia With Your Kids

Teens yearn for interactions that diminish frustration, embarrassment, and anger, and want specific guidance from doctors, therapists, or relatives about how to engage their loved one. Pressuring kids “to spend time” with the family member suffering from dementia may add stress to each encounter. Instead, parents and friends should encourage adolescents to find mutually satisfactory activities without forcing exchanges. Suggestions include movies (which can help ease the burden of communication), chess games, walks, or family photo album/ home movie viewing to revive good memories.

They want to understand the illness, but not in great detail, so energy spent obsessing about specific and often elusive diagnoses is better directed elsewhere. The more children want to learn, the more they will ask. Often, this evolves with their age, with older teenagers expressing a desire for more knowledge. Mostly, they want to feel secure that you will be able to manage, that you are getting help, and that despite this tragedy in your family, you will find happiness.

How and When to Tell Them?

Essentially, kids want to feel informed sooner rather than later, so don’t wait in an effort to protect them. It doesn’t work, because they will know something is wrong. Share the news in a conversation that allows them to express emotions and ask questions. The depth of details depends on the age of the child (kids 11 and older want more), but they have a very good sense of how much they can handle, and they can guide you.

Adolescents quickly grasp the actual or possible symptoms, because by the time the diagnosis rolls around, they’ve probably experienced a

lot of odd behavior. They usually feel enormously sad — yet relieved — to learn that an illness has caused the changes in their loved one. But some are surprised and reassured to hear how much those behaviors can vary from one patient to another. Adults need to remind kids that no two patients are exactly alike, and no single patient exhibits all symptoms. Unpredictability is the only constant. When children know this, they can attribute all unpleasant interactions with their beloved family member to the illness, which can ease their anguish.

Learn more at the website constructed specifically for kids, adolescents, and teenagers who have a loved one diagnosed with dementia: www.lifeandminds.ca/research/WhenDementiaisintheHouse

Checking in with Your Kids

This may seem obvious, but finding time to sit down and check in with your children is difficult — even when you don't have an ill family member to worry about. Adolescents tell us that they are extremely reluctant to approach parents under stress, for fear of adding to the problems. Therefore, the responsibility lies with you to set up regular check-in sessions. This may entail setting a specific day of the week when everyone sits down to dinner, or it may fall in those few minutes before you go to bed (because if you have teenagers, they often outlast you at night). Driving to and from school or practice is not ideal, but if that's all you can get, use it wisely. Have a hard time initiating conversation with your teen? Ask him to load some music onto your iPod (or burn a CD), then play it in the car. It's a fantastic way to bridge the gap.

WHEN DEMENTIA IS IN THE HOUSE

Helpful Messages to Reinforce

- Everyone feels the same emotions.
- Not only are they normal, they are completely acceptable.
- There is no wrong way to react to such a heartbreaking loss, and children need to hear this repeatedly.
- It might be helpful to admit that while you must remain strong for the family, these sentiments affect you, too. Typically, they include:
 - » Sadness
 - » Guilt
 - » Anger
 - » Shame
 - » Resentment
 - » Confusion
 - » Fear
 - » Frustration, frustration, frustration
- Make sure you know of a psychologist/family therapist who is ready to help, if necessary.
- Most often, teens just need you to hear them and hug them.

Empowering Kids to Help You — and the Patient!

Again, modeling life balance and an openness to managing as a team is most important. When friends say, “If there’s anything I can do to help, just let me know,” follow through. Let your kids hear you say, “My husband would love to listen to stories about the time you spent together. Would you be willing to pick up sandwiches and have lunch at home with him?” or “Next time you run to Costco, could you pick these items for us, and I’ll pay you back?”

Also tell your kids how you need their help. If it’s not related to caregiving, it may revolve around household chores that relieve you and make them feel like an essential part of the family — emotionally and

logistically. “Why doesn’t anybody help around here?” does not sound the same as, “Can we talk about who will be in charge of the trash in the house? And the dishes? And the dog? Can we brainstorm a system that works for all of us?” Taking on every detail because you feel terrible that your children are suffering sends you marching down the martyrdom trail. And nobody wants to follow you there.

How Much Caregiving Should Kids Do?

Caring for a loved one can be meaningful and positive — but only to a point. Adolescents reveal that caregiving does not connect them to the ill family member (besides the good feelings that arise from helping their parents), and can become enormously stressful if required too much. They must have time to live their own lives.

Physical demands, such as feeding and suctioning for a loved one who can’t eat or swallow, are difficult but sometimes less taxing than encounters that devolve into emotionally draining and negative memories. Caregiving at all levels can make children feel awkward, uncomfortable, and frustrated. Frequently, kids rely on you, the healthy parent, to act as a buffer. Despite the stress endured by all family members, however, helping to care for the person with dementia draws the children much closer to you. While not much changes with the patient, all agree that their relationship with the healthy parent evolves significantly.

Dementia Info Links

- <http://www.theaftd.org/frontotemporal-degeneration>
- <http://www.ninds.nih.gov/disorders/picks/picks.htm>

For updates to this content and a link to the site for adolescent caregivers:

- www.lifeandminds.ca/whendementiaisinthehouse



NICE

National Initiative for the Care of the Elderly

Initiative nationale pour le soin des personnes âgées

We care together

Ensemble pour le bien-être des aînés



NCE RCE

Networks of Centres | Réseaux de centres
of Excellence of Canada | d'excellence du Canada
2005-2010

National Initiative for the Care of the Elderly
263 McCaul Street, Room 328, Toronto, Ontario M5T 1W7
Telephone: 416-978-2197 | Website: www.nicenet.ca